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TITLE:

**Who cares about the parents? The implicit challenges of monitoring parental disability in child & adolescent services**

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## **Summary**

In accordance with legislation, childhood disability is routinely monitored in child and adolescent services; however there is no provision to identify parents with disabilities. The present study monitored the prevalence of parental disability and discusses implications and relevant issues.

## **Introduction**

Following the amendments to the Disability Discrimination Act (DDA) 2005, issues relating to disability and the promotion of equal opportunities have been prioritised on

both national and regional levels. The burden of proof now falls on organisations and services to offer equal access and opportunity to all individuals with a disability.

Since December 2006 the Disability Equality Duty (DED) set out a legal duty to all public health sector organisations to promote equal opportunities for the disabled by developing a Disability Equality Scheme (DES).

The Office for National Statistics (ONS) identifies the local area and focus for the present study as having one of the highest levels of illness and disability (25.3%) and economic deprivation in the UK, rated 3rd in index of multiple deprivation in 2004 (DPSR, 2004). This would imply that there is a considerable proportion of the local community who are covered by the DDA. Although the legal requirements are to improve accessibility and promote equal access, the plans to monitor disability and assess need are part of a DES three year plan and were not in place at the time of the present study.

Disability and health needs of children are identified through the assessment process, although parental disability is not routinely monitored. The DoH document 'Framework for partnership action on disability' (2004) states that over 40% of individuals with a disability experience major problems accessing services, and aside from the legal obligation to provide equality of service, it is important to consider the body of research which reviews the impact of parental disability and illness on the parenting role and the well being of the child (Glaser & Prior 1997, Olson 1996, Dearden & Becker 2004, Royal College of Psychiatrists, 2002), thus making it an important issue to address.

The needs of all family members should and need to be addressed appropriately bearing in mind the potential complexities all families bring, not just those with disabilities. However, families with a parent with a disability may be vulnerable to experiencing difficulties that may be complex due to experiencing additional needs.

If children of parents with a disability are not accessing services this suggests that there may be children who have needs that are not recognised.

Based on the existing policies and research reviewed presently, it was pertinent to assess and gain a snapshot of the proportion of parents<sup>1</sup> accessing a child & adolescent clinical psychology service who consider themselves to have a disability, and review the issues associated with this. A subsidiary aim was to establish whether clinicians perceive the child & adolescent clinical psychology service to be as accessible to individuals with a disability in comparison to non-disabled persons.

## **Method**

The present study was incorporated into the divisional action plan as part of the local NHS trust DES.

### **Setting**

This study was based at a child & adolescent clinical psychology department over a ten week period commencing in June. The department serves a catchment of 117,116 (Census 2001) in one of the areas of highest levels of deprivation in the country (Tinsley & Jacobs, 2006). The clinical psychology department provided services for children and adolescents up to the age of 16 (or 18 if still in full-time education). The general work of the department includes both community and hospital based referrals.

### **Participants & procedure:**

#### *Parents*

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<sup>1</sup> The term parents, carers and guardians will be used interchangeably throughout. For clarity 'parent' will be used in the majority, but will be used to also represent carers and guardians.

All families attending a first appointment within the department over a specified ten week period were eligible to take part in the study.

A 'patient information sheet' which was routinely given to parents was amended with an added box requesting parents to disclose whether they had a disability, and to state under which category this would fall. This was taken from recommendations in the DDA guidelines.

Names of new families attending the department were recorded and data from the questionnaires were later extracted from the clinical files and input onto a database.

### *Staff*

The target population was all staff working clinically within the department during the ten week period. The sample consisted of 26 staff members (24 female, two male). Ages range from 26 – 54 years old.

The survey was discussed and described at a team meeting prior to the commencement of the project. The staff survey was distributed at the first team meeting during the ten week period. Staff were requested to return the completed survey (if applicable) to the investigator's mail drop. A basic survey was developed that utilised a likert scale to measure staff opinion about accessibility of the service to individuals with disabilities. Staff were asked to rate accessibility of the service for these groups in comparison to the non-disabled population. The likert scale ranged from 'much less accessible' to 'more accessible', with the median point as 'equally accessible'.

No demographic or identifiable information was gathered.

## **Results**

During the data collection period, 139 new appointments were scheduled. Thirty-nine of these appointments were not attended (DNA) (28%). Twenty-nine appointments were

cancelled in advance (21%). A total of seventy-one families attended a new appointment within this period (51% of overall appointments). Overall, sixty-two parents were given the information sheets and requested to indicate whether they considered themselves disabled. Five individuals (8%) either chose not to participate or were unable to complete the target section of the information sheet. The response rate was 92%, N=57.

Two individuals indicated 'do not wish to respond', five indicated that they considered themselves disabled, and the remaining 50 indicated that they did not consider themselves to have a disability.

Calculation of 95% confidence intervals (1.5 – 16.2) highlights that the identified prevalence rate of 9 % is significantly lower than the expected local proportion of 25.3% ( $p \leq 0.05$ ).

Long Standing Illness (LSI) accounted for two of the five participants. The remaining three participants identified themselves as having a disability related to learning difficulties, physical disability and 'not specified'. There were no individuals who identified themselves as having a mental health related disability or sensory impairment.

The ONS does not breakdown statistics on disability sub-type in a way that could be meaningfully compared to the study data.

#### *Staff*

Nineteen clinicians self-selected to participate by returning the survey. This equates to an 80% response rate. Table I presents the results from the staff survey.

#### **Table I inserted here**

Analysis of skewness indicated that the data was normally distributed across all sub-groups except 'Sensory' which was positively skewed, thus all of the data is reported using median

and Inter-Quartile Range (IQR). Although this is a gross measure of staff perceptions, the descriptive analysis indicated that staff perceived individuals with a sensory related disability would find the service hardest overall to access in comparison with the other sub-types, with a median score of 2 out of 5, and an IQR of 1 point.

Individuals with a mental health related disability were perceived to find the service more 'easy to access' than individuals without a disability. 'Mental health' and 'learning difficulties' ratings produced the highest IQR of 2, showing the highest level of variance in rating.

## **Discussion**

The numbers of parents with disabilities accessing the child & adolescent clinical psychology department was lower than expected. Roth & BeVier (1998) recommend a 70% response rate for confidence in reporting accurate findings from the target population thus the response rate suggests that this was an accurate reflection of the families who *attended* their scheduled appointment. Based on these results, the outcome raises more questions than it answers. More specifically, why are the numbers so low?

As the present study is quantitative in design and not exploratory in nature, it is difficult to gauge where the true answer to this question lies. One explanation could be that barriers to access still currently exist. The underlying assumption may be that there may be physical barriers to access such as lack of information in Braille or difficulty acquiring a deaf sign language interpreter. This would be consistent with research by Steinberg *et al.* (1998) and Harris & Bamford (2001).

The service was also deemed by staff to be less than equally accessible to individuals with physical disabilities, which may be related to physical barriers such as parking and general accessibility issues, although this is a gross measure and it is difficult to assess precisely what is inaccessible about the service.

Explanations of a lack of appropriate resources/adjustments may not account for individuals with mental health problems particularly if staff rate the service to be more accessible to individuals with mental health related disability than those without.

Corrigan & Watson (2002) identified that stigma can be a barrier to access health and social services, significantly affecting the lives of individuals who are stigmatised in this way. The issue of stigma may also affect the monitoring of information such as disability and health, as individuals may not wish to disclose a disability for fear of impact on the services they may receive.

The DED is clear in its guidelines as to how to monitor disability and the definition of disability is clearly set out, as are the sub-categories of disability. However, the success of monitoring depends largely on whether this system is a good fit for the target population it is set up to monitor i.e. the validity of the approach - is this a case of ineffective monitoring?

Petrie & Weinman (1997) postulate that there is no unifying concept of disability and definitions and measurements of disability are diverse, which may lead to discrepancies that could identify the same person as both disabled and non-disabled, thus how disabled is disabled? This lack of clarity may not only significantly affect monitoring accuracy, it may also affect illness identify and self-concept. Elaborating further on this concept, Murphy (2005) discusses the issue that changing norms continue to define and redefine the meaning of disability – which in reality may prove a complex challenge to monitoring disability and more practically, the financial allocation of service provision.

Oliver's (1990) concept of a 'social model of disability' has transformed perspective and understanding of disability and whilst this is referred to throughout the DED and accompanying literature, taking a social model of disability approach to monitoring is



inherent with difficulties, it cannot, by definition be generalised to encapsulate all. This raises questions about measurement and the use of arbitrary discrete classifications, particularly in a climate which aspires to utilise a social model of disability. In the present study it is assumed that only those who indicated that they were disabled are disabled, although many may have a disability or complex health needs which they subjectively do not consider to be disabling.

A possible explanation for the low attendance rate of parents with disabilities may be due to the need not existing; that the need may be met elsewhere, for example parents with LD accessing specific LD services (McGaw & Newman, 2005).

Finally, it is worth reflecting on the proportion of parents and families who did not attend from the outset. Although cancelled and DNA appointments are always likely to account for a significant minority of scheduled appointments, it is possible that parents with disabilities do not attend from the outset for the reasons reviewed here. This is indeed a perennial problem that is implicit within all data monitoring, you can only count those who stand up to be counted. In this case, it is possible, however unlikely that the 49% of non attendees had a disability and chose not to attend for reasons of accessibility or stigma.

### **Limitations & future directions**

A limitation of the methodology is the small sample size and by this means should serve as a preliminary investigation with future studies expanding the monitoring period. This low sample size also restricted the level to which the data can be compared to national statistics, and can only be meaningfully interpreted as a snapshot of a service highlighting potential difficulties in this method of monitoring at a time when this matter is particularly politically pertinent. It may be appropriate in future to utilise the Common Assessment Framework (CAF) form to inform practice and enable recording of relevant factors such as parental health and disability.

Qualitative research adopting a social model of disability involving those who identify themselves as disabled (service-user involvement as recommended by the DED) is both necessary and would give a clearer picture of what further service development may be beneficial in promoting equality of access.

## **Conclusion**

Utilising the ‘social model of disability’ (Oliver, 1990) as an approach to assess need and has evolved to be a gold standard when working with individuals with a disability. Reflecting on the outcome and discussion within the present study it is clear that a social model of disability, as one would expect, does not translate easily when trying to develop a standardised generic system of monitoring disability.

The DED stipulates that service-users must be involved at all levels when developing and delivering the DES, and although this may not necessarily be enough to counteract the potential pitfalls of using a value-laden discrete categorisation system which is heavy with implicit assumptions. This system can, after all, be a very disabling approach and reinforces the arbitrary divide between the so-called ‘able bodied’ and those who are less so. The challenge then, is to promote awareness of the issues that may face individuals with disabilities and their families, and how this impacts on everyday living – and deal with this accordingly, as this is the real priority.

## **References**

Corrigan, P. W. & Watson, A. C., (2002) Understanding the impact of stigma on people with mental illness, *World Psychiatry*, 1 (1): 16–20

Department of Health / Disability Rights Commission (2004) *Framework for partnership action on disability*, available online at

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4083501](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4083501)

Department of Social Policy and Social Research –DSPSR (2004) *English Indices of Deprivation*, University of Oxford: Oxford

Dearden, C. & Becker, S. (2004) *Young carers in the UK*, Carers UK: London

Disability Rights Commission (2006) *Disability Equality Duty*, available at <http://www.dotheduty.org/>

Glaser, D. & Prior, V. (1997) Is the term child protection applicable to emotional abuse? *Child Abuse Review*, 6, 315-329

Harris, J. & Bamford, C. (2001) The Uphill Struggle: services for Deaf and hard of hearing people - issues of equality, participation and access, *Disability & Society*, 16 (7), 969-979

Home office / Department for Work and Pensions (2005) *Disability Discrimination Act*, HMSO: London

Jacobs, M., & Tinsley, J. (2006) *Ethnicity and deprivation: a regional perspective*, Office for National Statistics, accessed on 05.10.2007 at <http://www.statistics.gov.uk/CCI/article.asp?ID=1560&Pos=2&ColRank=1&Rank=192>

McGaw, S & Newman, T. (2005) *What works for parents with learning difficulties?* Barnardos:  
Ilford

Murphy, J. W. (2005) Social norms and their implications for disability, *Journal of Social  
Work in Disability & Rehabilitation*, 4, 153-163

National Office for Statistics (2001) *Primary Care Trust ward summary*, Source: 2001 Census  
Table KS08 © available at  
[http://www.manchester.gov.uk/planning/studies/census/northpct.htm#Table%20  
4](http://www.manchester.gov.uk/planning/studies/census/northpct.htm#Table%204)

Oliver, M (1990) *The Politics of Disablement*, Macmillan: Basingstoke

Olsen, R. (1996) Young Carers: challenging the facts and politics of research into children  
and caring, *Disability & Society*, 11 (1) 41-54

Petrie, K., & Weinman, J. (Eds) (1997) *Perceptions of Health & Illness: current research and  
applications*, Harwood Academic Publishers: Singapore

Royal College of Psychiatrists (2002) *Patients as parents: Addressing the needs including safety of  
children whose parents have mental illness*, council report, available at  
<http://www.rcpsych.ac.uk/publications/collegereports/cr/cr105.aspx>  
[www.rcpsych.a  
c.uk/publications/cr/council/cr105.pdf](http://www.rcpsych.ac.uk/publications/cr/council/cr105.pdf)

Roth, P., & BeVier C. (1998) Response rates in HRM/OB survey research: norms and  
correlates, *Journal of Management*, 24 (1) 97-117

Steinberg, A., Sullivan V., Loew, R. (1998) Cultural and linguistic barriers to mental health service access: the deaf consumer's perspective, *American Journal of Psychiatry*, 155 (7) 982-984

**TABLE**

**Table I 'Staff ratings of accessibility of the service'**

	Minimum	Maximum	Median	Inter-Quartile Range
Physical	1.00	5.00	3	2-3
Sensory	1.00	4.00	2	1-2
Mental health	1.00	5.00	3	2-4
LD	1.00	5.00	2	2-4
LSI	2.00	4.00	3	2-3